

54th ENCR Steering Committee (SC) Meeting Summary

Date and time: 3 June, 2014, Ispra, Italy 8:45-17:00

Attendees Present: ENCR SC, European Commission Joint Research Centre (JRC), Invited Guest from EORTC, Belgium

EC invited guest

EORTC representative gave a presentation regarding quality of care, entitled: 'EORTC outcome research data linkage project between clinical trials, cancer registries and health administrative data'. Potential collaboration with the ENCR was discussed.

Report on ENCR activities

- **Update from the Working Group on Quality Checks**

Action: The final document on quality checks will be finalised and presented at the 2014 ENCR Scientific Meeting and General Assembly in November.

- **ENCR Factsheets**

Action: Finalise the factsheet on lung cancer and start the preparation of a new factsheet on breast cancer.

- **ENCR Website and Newsflash:** It is important to update regularly the list of publications with registries' data, posted on the website. Advice on the criteria for selecting publications was requested from the SC.

Action: The JRC will make a proposal to the SC regarding the reorganisation of the 'Publications' page of the ENCR website.

- **Proposal on the report for site visits**

Action: An updated structure of the ENCR "Review Report" will be produced for site visits to registries, merging two previously existing documents.

- **Recommendations document on haematological malignancies**

Action: The summary document was published and the relevant tables will be added to the ENCR web site.

- **ENCR 2014 SC elections:** Elections will be held for the five open positions in the SC. The deadline for sending a candidature is July 30, 2014 and the elections will be held 1 September to 15 October 2014. Cancer registries that are not population-based or have not filled one of the two membership surveys (2010 or 2014) will have no voting rights. Countries where registries have merged and are now under a national registry, will have only one vote.

Action: The JRC will send the registries the election documents approved by the SC.

- **Requirements for ENCR membership:** The ENCR membership requirements will remain as stated on the ENCR web site (<http://www.enccr.eu/index.php/who-we-are/membership>).

Action: The new SC will revisit the issue and a new proposal will be formulated.

- **Update on the JRC/IARC collaboration:** The JRC updated the SC on the state of the contract negotiation with IARC for the transfer of the European Cancer Observatory (ECO) website, the administrative issues involved and potential alternative scenarios.

Action: The ENCR SC will write a letter to the JRC and IARC directors emphasising the importance of, and urgency to finalise the negotiations and ensure timely completion and transfer of the ECO website.

ENCR Scientific Meeting and General Assembly (GA)

The 2014 ENCR meeting and GA will be held 12-14 November 2014 in Ispra. A call for abstracts and instructions for submission has already sent to the registries. The agenda for discussion at the GA will include a report on ENCR activities and developments since the last meeting, the JRC's new role and achievements, plans for the future and collection/review of European registries' needs. ENCR membership and voting rights as well as the composition rules of the SC will be discussed.

Action: Revise the meeting agenda on the basis of received contributions or presentations from the registries.

Action: Oral presentations and posters will be evaluated by the members of the SC during the meeting.

Other European and International Consortia

The JRC introduced the Cancer Control Joint Action (CanCon), which during the period 2014-2017, aims at reducing the cancer burden in the EU through the following actions: 1) improving the quality of cancer care among member states, 2) improving the quality of life of cancer patients and survivors with proposals on survivorship and ensuring reintegration and palliative care, and 3) addressing inequalities at various levels of cancer control. JRC will host one of the CanCon platforms.

IARC announced it is developing a new membership website, an ICD-O-3 online and a TNM staging tool.

Updated analysis of the proposed EU data protection legislation

The Council has not decided yet which legislative tool will be used for data protection (directive or regulation). ESMO and the Commission have helped to promote favourable legislation. Currently, full consent is needed for the use of personal data, unless the purpose is of 'high public health interest'. The ENCR and the JRC are closely following the issue to ensure it will not negatively impact cancer registration and epidemiological studies.

AoB and date of the next meeting: The 55th SC meeting will be held 12 November 2014 in Ispra, Italy.